

**REPORT TO THE TWENTY-THIRD LEGISLATURE  
STATE OF HAWAII  
2006**

**PURSUANT TO SECTION 321-291, HAWAII REVISED STATUTES  
REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN  
ANNUAL FINANCIAL REPORT FOR THE  
NEWBORN METABOLIC SCREENING SPECIAL FUND**

**PREPARED BY:  
STATE OF HAWAII  
DEPARTMENT OF HEALTH  
NOVEMBER 2005**

## **EXECUTIVE SUMMARY**

The Hawaii Newborn Metabolic Screening Program (NBMSP) is administered by Children with Special Health Needs Branch, Hawaii State Department of Health. NBMSP has statewide responsibilities for assuring that all infants born in the State of Hawaii are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases that are added to the screening panel. This program tracks and follows up on infants to assure satisfactory testing and to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment. The objectives are to prevent mental and growth retardation, severe health problems, and even death, resulting from disorders detectable through newborn metabolic screening.

In 1996, legislation was passed, H.R.S. §321-291, which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

The Hawaii Administrative Rules, Chapter 11-143, revised and adopted on November 20, 2003, reflect the following changes:

- Expansion of the newborn metabolic screening testing battery to include tests for:
  - Phenylketonuria (PKU)
  - Congenital Hypothyroidism
  - Galactosemia
  - Hemoglobinopathies
  - Congenital Adrenal Hyperplasia (CAH)
  - Maple Syrup Urine Disease (MSUD)
  - Biotinidase Deficiency
  - Amino Acid Disorders
  - Fatty Acid Oxidation Disorders
  - Organic Acid Disorders
  - Urea Cycle Disorders

- Newborn screening fee increased from \$27.00 to \$47.00 per specimen collection kit beginning September 1, 2003. The fees are deposited in the newborn metabolic screening special fund, which pays for the following expenses:
  - Centralized laboratory testing for the thirty-one disorders
  - Repeat testing for initial specimens collected at less than 24 hours of age
  - Confirmatory testing up to the point of diagnosis if specimens are sent to the designated testing laboratory
  - Specimen collection and handling
  - Overnight mailing costs of the initial specimens to the testing laboratory
  - Newborn Metabolic Screening Program staff salaries and fringe benefits
  - Contracted nutritionist, pediatric metabolic specialist; pediatric endocrinologist; and pediatric hematologist services
  - Screening and diagnostic costs for the uninsured indigent
  - Tracking and follow-up, and the administration of the statewide newborn screening system
  - Continuing education
  - Educational materials
  - Quality assurance
  - Equipment
  - Indirect costs
  - Administrative overhead

The attached financial report for FY 2005 (July 1, 2004 to June 30, 2005), required by § 321-291, HRS, identifies all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund and the purposes for each expenditure.

### Report on Non-General Fund Information

<b>Department:</b>	HEALTH	<b>Date:</b>	9/22/2005
		<b>Prepared by:</b>	Roy Sugimoto
		<b>Phone:</b>	586-4570

**Name of Fund:** Newborn Metabolic Screening Special Fund  
**Legal Authority:** Section 321-291, HRS  
**Fund Type (MOF):** B  
**Approp. Acct. No:** S 302 H

**Intended Purpose:**

This fund is to be used for payment of its lawful operating expenditures, including, but not limited to laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

**Current Program Activities:**

The Newborn Metabolic Screening Program (NBMSPP) has statewide responsibilities for assuring that infants born in the State of Hawaii are satisfactorily tested for 31 disorders which can cause mental and growth retardation and even death, if not detected and treated early in the newborn period. NBMSPP tracks and follows-up on infants to assure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities are assessment, quality assurance, continuing education, and standard setting.

Financial Data		
	FY 2005	FY 2006
Beginning Cash Balance	554,078.45	752,678.28
Beginning Encumbrances	138,112.79	202,252.22
Revenues	943,091.87	
Internal Transfers	0.00	
Expenditures	690,042.42	
Transfers (List Each Transfer by JV# and Date)		
JM2157 (11-12-04)	54,449.62	
Net Total Transfers	54,449.62	
Amount Derived from Bond Proceeds		
Ending Cash Balance	752,678.28	
Amount Required for Bond Covenants as of 7/1/03		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/03.		

HTH

## PURPOSES FOR EXPENDITURES FOR FY 2005

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 FTE)	\$196,141.33
B.	Car Mileage	392.80
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	399,242.64
B.	FedEx services to deliver specimens to the testing laboratory	28,888.17
C.	Back-up batteries for the computers	281.22
D.	Fax machine maintenance	321.37
E.	Stationary and office supplies	1,034.55
F.	Printing of newborn metabolic screening rack cards	1,406.20
G.	Laboratory services for the uninsured	1,257.76
III.	Continuing education	
A.	2004 Newborn Screening and Genetic Testing Symposium, Atlanta, Georgia, 5/3/04–5/6/04	324.00
B.	Translating Tandem Mass Spectrometry Results from Laboratory to Follow-up, Durham, North Carolina, 12/4-12/11/04	1,674.70
C.	Ross Metabolic Conference, Savannah, Georgia, 4/6-4/10/05	1,570.57
D.	MCH Training Institute, Clayton Missouri, 4/29-5/4/05	338.50
E.	In-service to nurses, physicians, and laboratory staff on Maui, Kauai, and Big Island	90.00
F.	Registration fee for Marshallese workshop	45.00
G.	Bilingual Access Line translation services	82.00

IV.	Genetic services at Hawaii Community Genetics	50,000.00
V.	Endocrine services for the uninsured	512.16
VI.	Air and ground transportation for endocrinologist services on the Neighbor Islands and Neighbor Island travel for newborn screening presentations	6,439.45
<b>TOTAL</b>		<u>\$690,042.42</u>

JV #JM2157 Assessments for central services and administrative expenses for FY 04	\$54,449.62
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BEGINNING ENCUMBRANCES FY 2006

Personnel	\$13,528.00
Mileage	100.00
Oregon State Public Health Laboratory	130,018.00
FedEx courier services	2,500.00
Endocrine services for the uninsured	122.53
Laboratory services for the uninsured	592.89
Neighbor island travel	200.80
Shuttle to and from the airport for the MCH Training Institute	60.00
Registration fee for the 2005 ASCLS/CLMA Annual Meeting	130.00
Assessments for central services and administrative expenses for FY 2005	55,000.00
<b>TOTAL</b>	<u>\$202,252.22</u>